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SCIENTIFIC SECTION



How do patients perceive the British orthodontic society online information resource about orthognathic treatment? A qualitative study

Jennifer Kettle ¹, Zoe Marshman ¹, Philip E. Benson ¹, Caroline McCarthy ², Gurpreet Pye ³, Jonathan Sandler ⁴, Lindsay Winchester ⁵ and Andrew Flett ⁶

¹School of Clinical Dentistry, University of Sheffield, Sheffield, UK; ²Montagu Hospital, Mexborough, UK; ³Dundee Dental Hospital and School, Dundee, Scotland; ⁴Chesterfield Royal Hospital NHS Foundation Trust, Calow, UK; ⁵Queen Victoria Hospital NHS Foundation Trust, West Sussex, UK; ⁶Nottingham University Hospitals NHS Foundation Trust, Nottingham, UK

ABSTRACT

Objectives: To explore the accessibility, usability and relevance of the British Orthodontic Society (BOS) online information resource (OIR), Your Jaw Surgery.

Design: Qualitative, cross-sectional study.

Setting: 5 UK sites.

Participants: Patients before, during and after treatment for non-cleft skeletal discrepancy.

Methods: Patients were identified at joint clinics and recruited after having time to view the OIR. Semi-structured interviews were conducted with 17 patients (aged 16–46 years). The interviews were transcribed and thematic analysis was undertaken using a framework approach.

Results: The main themes identified were the overall usefulness, personal relevance and positive perceptions of the OIR. The OIR was seen to be useful for patients considering treatment, and potentially useful for patients undergoing treatment. Participants were looking for a personally relevant resource that would give them the best possible idea of how they would look and feel after surgery. The OIR was perceived as trusted, positive and reassuring.

Conclusions: Patients at different stages of treatment found the OIR helpful and reassuring. Clinicians may find it useful to direct patients to the OIR to complement a professional consultation, but should be aware that patients may perceive it as presenting a positive image of the long-term benefits of orthognathic surgery.

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Introduction

Orthognathic surgery is a recognised and well-established treatment for major skeletal discrepancies (Cunningham and Johal 2015). The length of orthodontic treatment associated with orthognathic surgery is usually between 2 and 3 years, so patients must be well prepared for what is involved. Research suggests that orthognathic treatment has relatively low morbidity and the risks of serious complications are rare. However, while the prevalence of adverse effects is low, these can lead to permanent damage. The most common surgical risk is damage to the maxillary and/or mandibular branches of the trigeminal nerve. This can result in a permanently altered or in rare cases, a complete loss of sensation to the lips or other structures innervated by the damaged nerve (Royal College of Surgeons 2013).

Individuals considering treatment must assess these risks carefully, and the impact treatment may have on their lifestyle, as well as that of their partner and families. It is the clinician's responsibility to provide all necessary

information to the patient about orthognathic treatment, to allow them to weigh up the potential benefits and risks of undergoing treatment. Patients with more realistic expectations are more likely to be satisfied with their appearance post-treatment (Chen et al. 2002; Espeland et al. 2007). Patients are also more likely to be satisfied when they are forewarned about negative experiences they can expect post-treatment (Nurminen 1999; Travess et al. 2004; Alkharafi et al. 2014).

Clinicians are adept at providing factual, scientific information but sometimes omit details as to how patients should cope physically and mentally with the treatment and recovery from surgery (Bekker et al. 2010). Research has shown some patients have unmet needs in terms of support for decision making and managing the emotional effects of orthognathic treatment (Stirling et al. 2007). A lack of practical advice can encourage patients to seek information from other sources, such as Internet discussion boards, which can lead to patient confusion and dissatisfaction (Bhamrah et al. 2015).

Flett et al. (2014) investigated how far a British Orthodontic Society (BOS) DVD helped patients to make decisions about orthognathic surgery. The DVD was felt to provide trusted information about orthognathic surgery however, there were some practical issues using the DVD. Some participants reported that the menu was unclear and some suggested that the DVD was repetitive or 'long-winded'. Participants also found it difficult to compare the before and after pictures, as a complete set of pictures was rarely seen. There are also practical difficulties updating and distributing a new DVD, while an online resource can be continually amended.

Following this research, the BOS commissioned a working party to design an online information resource (OIR). Previous research suggests that online information about orthognathic surgery is of low quality, biased and not properly evidenced based (Aldairy et al. 2012) and is not always trusted by patients (Flett et al. 2014). The hope was that by embedding the OIR within the BOS website, it would provide provenance to the resource. The OIR was designed to contain general information on the benefits and risk of orthognathic treatment and includes: videos showing stages in the treatment process (Patient Journey (Figure 1)); patients narrating their own experiences, including before and after photos (Patient Stories (Figure 2)); animations of surgery (Your Surgery Explained (Figure 3)); and videos of retainers and aftercare advice (Other Resources (Figure 4)).

The OIR, 'Your Jaw Surgery', has been embedded on the website since March 2016. By December 2016 the videos had been viewed 54,000 times, in 98 countries, averaging about 3900 views per month (Vimeo Statistics Report 2016–2017). However, we do not know if what has been created is of use to patients. Therefore, the aim of this project was to ascertain patients' perceptions of the OIR through qualitative enquiry. The specific objectives were to:



Figure 1. Video of joint clinic from Patient Journey.

Jasvinder's Story



- Why I chose jaw surgery
- What were braces like
- How was surgery for me
- How I feel now

Figure 2. Video of patient from Patient Story.



Your Surgery Explained

Here are animated films for you to clearly see the different types of surgery

[Find out more](#)

Figure 3. Animation still from Your Surgery Explained.

Your Jaw Surgery

Diet Sheet

After your surgery it is important you eat well as healing requires good nutrition. Please see the following advice:

Figure 4. Aftercare advice from Other Resources.

- Identify a range of patients with facial skeletal deformity who are considering or who have undergone orthognathic treatment to treat facial skeletal deformity
- Conduct qualitative interviews to explore views about the OIR in the areas of:
 - o Accessibility and usability
 - o Navigation around the resource
 - o Relevance of digital content
- Provide recommendations to improve the OIR from patient perspectives

Participants and methods

This was a cross-sectional qualitative study. Ethical approval was obtained from South East Coast – Brighton & Sussex Research Ethics Committee (Ref. 16/LO/0942). Purposive sampling was undertaken to include adult patients of different ages and genders who were considering, undergoing or had completed orthognathic treatment. Patients with syndromes, complex medical history or cleft lip and palate, and patients considering re-operation were excluded. Patients who met the study criteria were identified by clinicians in Sheffield, Chesterfield, Doncaster, East Grinstead and Dundee. Patients were sent a link to the OIR, and the research assistant contacted potential participants to arrange an interview. Informed consent was obtained at the time of the interview.

Individual semi-structured interviews were carried out by the research assistant using a topic guide. The topic guide was produced from the literature and developed during the research to further explore themes. Six interviews in South Yorkshire and Derbyshire were carried out at participants' homes or at the University of Sheffield. Other participants took part in telephone interviews. Interviews took between 14 and 40 minutes. The interviews were carried out by a research assistant with doctoral-level training in qualitative research. Interviews were audio-recorded and transcribed verbatim.

Thematic analysis using a framework approach (Ritchie et al. 2003) was undertaken by the research assistant, and the emerging themes discussed with the project team. The preliminary findings were also presented to a University of Sheffield research group for further discussion and to inform the recommendations. Following the interviews and analysis, an evaluation questionnaire was developed to collect feedback from patients on the OIR.

Results

A purposive sample of 30 patients who met the inclusion criteria were identified (Table 1). The research assistant

Table 1. Participants by age, gender and stage of treatment.

Age	Gender	Stage of treatment			Total
		Pre Rx	In Rx	Post Rx	
16–19	Female	2	1	1	4
	Male	2	2		4
20+	Female	2	2	2	6
	Male		1	2	3
Total		6	6	5	17

Table 2. Participants by malocclusion.

Class I AOB	Class II	Class II AOB	Class III III	Class III AOB	Class III/ asymmetry
1	3	1	8	2	2

monitored the patient characteristics of the sample during the recruitment process. In order to achieve a sample comprising participants of different ages and genders, and at different stages in the treatment process, the research assistant contacted the participant identification centres to update clinicians on the patients required to meet gaps in the sampling frame. Seventeen participants were interviewed, and recruitment stopped at this point as no new data emerged.

Fourteen participants were White, one was Afro-Caribbean, one was Asian and one was Mixed. Prior to surgery, a range of malocclusions were presented in the individuals interviewed (Table 2). Sampling was intended to include different malocclusions, although it was not possible to achieve a balance of malocclusion types, as well as stages in the treatment process.

Themes

The conceptual framework was developed during the analysis and three themes emerged regarding patient perceptions of the OIR (Table 3). Each theme will be discussed with anonymised quotes for illustration.

Table 3. Themes identified from the interviews.

Overall usefulness of the OIR
– Clear and easy to use
– Benefits of being online
– Value of content
Personal relevance of OIR
– Relevance of timing
– Looking for personally relevant resource
Positive perceptions of OIR
– Trusted resource
– Balanced in terms of benefits outweighing likely side-effects and risks
– Encouraged by positive stories
– Reassuring patients

Theme 1: overall usefulness of the OIR

Clear and easy to use

Participants in the current study were positive about the layout and usability of the OIR. The layout was described using terms such as 'clear', 'simple' and 'logical'. The OIR was also seen to be 'easy' to use and navigate around.

It was quite straightforward to navigate through the pages. (M, 21, post-treatment)

Benefits of being online

Participants reported accessing the website on computers, tablets and smartphones, which fitted into everyday life. This was more practical than a DVD.

If I was given a DVD, I'm not sure if we would watch it, because it's sort of, if you go on a website you can quite easily click in and out of things, just if you don't think it's relevant to you and it's faster to do that. (F, 27, in treatment)

Participants also described being able to show the OIR to others, in order to help them understand the process of orthognathic treatment.

It was so short, you can whip out your phone and show them the video and then they'd be, like 'Oh ok, we understand how it's done now.' (F, 16, in treatment)

Participants were aware that family members also wanted to know what was involved with orthognathic surgery, and might have additional concerns. They also spoke about preparing their parents and partners for what to expect.

When we saw Lauren and her mum's story it was quite reassuring because I had my mum sitting next to me at the time and she was quite worried about it. Just because she doesn't like the idea of me having to go through surgery. But seeing how happy they both were with the result seemed to help her quite a lot as well so that was reassuring. (F, 16, pre-treatment)

And my mum, and my family, I think I showed them the video of how swollen the boy's face was and I was like 'you can't be shocked when I wake up'. And that's what I showed them. (F, 24, pre-treatment)

Being able to share this information with family members was an important benefit of 'Your Jaw Surgery' being online.

Value of content

Participants were positive about the information provided on the OIR as a whole, and largely positive about the sections they had looked at.

I think it basically covered everything you'd need to know from people's experience to what's potentially going to happen and other people's experience of aftercare and what you can sort of expect. (F, 23, post-treatment)

Participants reported that it was helpful to hear about other people's experiences in the Patient Stories and see patients post-surgery in the Patient Journey videos and get a realistic idea of what to expect. Watching animations in Your Surgery Explained showed what was going to happen in depth and having access to information about what to expect post-surgery in Other Resources provided support during treatment.

You can talk to parents and stuff but it's not the same as someone who's shared that experience and then you are watching it and it's quite nice to see someone else talking about it. (F, 20, post-treatment on Patient Story videos)

They were interesting as well because you see folk with braces all the time now. But yeah, how did it all work, you don't know. But watching that gave me another insight into what I'm going to have to go through. (F, 46, pre-treatment on Patient Journey videos)

They were really easy to understand, quite informative, very clear, good diagrams. It just showed straightaway what was happening. (M, 20, in treatment on Your Surgery Explained videos)

Like I found the best one was what to expect when you wake up from surgery, all like the step-to-steps, after so many weeks you should... It's nice to see them sort of things like, it puts the thing in your mind so it's not so much uncertainty going into surgery, you know what might happen. (M, 18, in treatment on Other Resources)

It was found that the different sections worked well together. Several participants did not think the OIR needed to be improved.

The things that were there were fine, I can't suggest anything you could do to improve it. (M, 30, post-treatment)

I think it covers everything. (F, 27, in treatment)

Some participants mentioned ideas for a suggested improvement, but these were ideas for additional content and did not refer to significant issues. Examples included additional patient story videos and additional videos about the patient journey (see Recommendations to BOS below). Participants would recommend the OIR to others based on its usefulness.

I do think it's a really good website and I would recommend it to anybody who was thinking of getting surgery. (F, 46, pre-treatment)

I think it would answer a lot of questions for somebody who hasn't had the surgery. (F, 23, post-treatment)

Theme 2: personal relevance of OIR

Relevance of timing

Participants thought the website was helpful at the stage of considering treatment.

Back when I was making my decision this would have been helpful. (M, 19, in treatment)

For participants who had made a decision but not started treatment, or who had recently started treatment, the OIR was helpful in addressing concerns they had about orthognathic treatment.

It's still handy for somebody at my stage of the treatment because you're still getting information about things that are about to happen. And so it just makes you more well-informed. (F, 27, in treatment)

The OIR clarified what was involved with orthognathic treatment. Some participants viewed the OIR as primarily a resource for those making a decision about treatment, and felt they were already sufficiently informed.

I did a lot of research before I actually looked on your website so there's nothing that really stood out to me or surprised me or anything like that. (F, 34, in treatment)

However, the aftercare videos and advice includes important information for patients in treatment, and participants were not always aware of this.

Looking for personally relevant resource

Participants were looking for a personally relevant resource. This involved selecting videos to watch on the basis of malocclusion or surgery-type, as well as shared demographic characteristics.

I mainly watched ones of females because I think they often might focus on, like, the cosmetic side of it and how they found things afterwards. And I've also watched pretty much all the ones for the open bite because that's the type of surgery that I'm getting. (F, 16, in treatment)

Most participants felt there were enough relevant videos, although some younger participants suggested more teenagers.

I'd also quite like to see some more younger people. (F, 16, in treatment)

So I'm like 'oh, he's pretty much an adult and I'm making the decision as a teenager'. So maybe looking at what teenagers think about it. (F, 16, pre-treatment)

Therefore, providing an age range for patients during their treatment may help prospective patients identify with the videos (see Recommendations to BOS below).

Participants were able to see how faces had changed as both forward-facing and profile photos are shown

(Figures 5 and 6). Participants were sometimes concerned about how their faces would look post-treatment, and wanted to get an idea of how they might look from viewing before and after photos, which were of particular interest.

I think it's really good on the patient stories as well how they have the before and after pictures of how it's a step-by-step. (F, 20, post-treatment)

Specifically I wanted to look at before and after pictures of my, of the open bite that I had, do you know what I mean? And see how their surgery turned out. (F, 34, in treatment)

Participants wanted to have an understanding of how they would feel before and after the surgery, and found the Patient Journey videos useful for this.

The aftercare, the Toby one ... it showed his breathing and how he was talking afterwards and he was also so, like, positive about it. So it made me feel good that I'd be able to get dressed and ... come into the doctor's office after surgery. (F, 16, in treatment)



Figure 5. Example of photographs included with Patient Story video.



Figure 6. Example of photographs included with Patient Story video.

A few suggested additional videos, showing patients talking about how they felt just before surgery, and soon afterwards (see Recommendations for BOS below).

Theme 3: positive perceptions of OIR

Trusted resource

Participants demonstrated different attitudes to information. Participants had received information about orthognathic treatment from clinicians, and generally felt that the process had been clearly explained.

My orthodontist she's been really good. I just feel that she's been able to explain things far better to me and I've got a far better understanding of it. (F, 46, pre-treatment)

I think the leaflets I got from my orthodontist were good, it gave me an idea of what to expect, why I should have it, what it involves. (M, 21, post-treatment)

In addition to this information, some participants who were post-treatment remembered wanting to find out as much as possible about orthognathic treatment and recalled viewing a range of sources, including YouTube and patient blogs.

Before this website was created I used to go on YouTube and watch videos of people's experiences. (F, 20, post-treatment)

I looked at a lot of blogs, I was quite pleasantly surprised to find a lot of blogs on jaw surgery which was really good to see. (M, 21, post-treatment)

Others deliberately avoided looking for information, or prioritised information recommended by their orthodontist or surgeon.

I don't really want a lot of detail to be honest, I'd rather just let them get on with the main side of the surgery themselves. (M, 20, in treatment)

I didn't want to risk going onto an unprofessional website and seeing 'oh no, it will ruin your life forever' because that's not overly helpful. We just wanted to go with the professional one that had been recommended. (F, 16, pre-treatment)

As a resource provided by the BOS and signposted by clinicians, 'Your Jaw Surgery' was seen as trustworthy.

I was able to trust the information, which is something that I kind of struggle with a lot of the time when I'm on the Internet. But when it's something like that you know it's going to be, like, the truth, sort of, thing. (F, 27, in treatment)

This was supported by the content, for example the patient journey videos, which reflected participants' own experiences.

They were pretty accurate. (M, 20, in treatment)

They're a quite realistic, I know it's real but like it's quite similar to what I had. (F, 20, post-treatment)

Realistic accounts about experiences in the Patient Stories were also seen as more trustworthy.

It was good to be informed because ... they didn't make out it was all absolutely fine and they woke up and they were not in any pain. They were quite honest that it was quite sore and everything ... they were really honest and that was really good. (F, 24, pre-treatment)

Benefits seen to outweigh likely side-effects and risks

Participants perceived the benefits of surgery outweighed the likely side-effects and risks.

It's going to be some pain, some discomfort for the first maybe a week or two weeks ... three weeks, but the benefits at the end of it will be worthwhile. (M, 20, in treatment)

The most common risk mentioned was numbness to the lower lip, and participants who mentioned this did not appear too concerned. Some participants felt that there was more detail about the benefits than the actual risks of surgery. This was perceived as a good thing in terms of encouraging people to have a treatment that could improve their lives and putting risks in perspective.

If you were to include sort of equal risks and benefits I think it would perhaps put people off ... I think it's good for them to show the clear benefits and how happy it's made people. (F, 16, in treatment)

As orthognathic surgery was seen to be relatively low-risk, and provide important benefits, several participants felt that this should be the message from a BOS OIR.

Encouraged by seeing positive stories

The patient stories on the OIR show the positive impact of treatment on people's lives. Participants who had not yet had surgery suggested that the patient stories represented a range of experiences, and presented an overall positive picture of orthognathic treatment.

Not one of those people had a bad end result ... Not one of them that I watched. (F, 46, pre-treatment)

This positive message shaped participants' expectations of surgery.

That's what I'm kind of expecting, to be scared before the operation and then after the operation be happy with the results. (M, 19, pre-treatment)

Reassuring patients

The most common response to viewing the OIR for patients who were pre-treatment or in treatment was a feeling of reassurance. This related to the overall tone of the OIR and the results of other patients' treatment.

But it was quite, sort of, reassuring to hear that even if there is numbness and things like that, the majority of people think, you know, that it's not a problem sort of thing. (F, 27, in treatment)

Those who were post-treatment suggested they would have found the OIR a 'comfort' and would have had a better idea of what to expect.

Discussion

This qualitative study investigated how patients at different stages of orthognathic treatment perceived 'Your Jaw Surgery'. In a review of a BOS DVD, Flett et al. (2014) found that the menu could cause confusion. In contrast the OIR was seen as easy to use, with a clear layout and information provided in a straightforward way. Participants accessed the OIR using various devices, and did not report any problems. An online resource fitted easily into people's lives. Several participants did not feel there was any need for improvement in the content provided. Others suggested adding additional examples, or videos and photos that provided more detail about previous patients' experiences.

This resource was seen as valuable for patients considering orthognathic treatment, as it provided information about what happened during treatment, as well as experiences of patients. Participants who had started treatment had mixed views about the ongoing usefulness of the OIR; some felt it would be useful to return to the OIR nearer the time of their surgery for continued reassurance and when information about aftercare was more relevant, while others felt sufficiently informed. Where videos and information from the other resources section may be helpful for patients who are in treatment, clinicians could direct patients to specific resources.

Participants trusted the OIR as a resource provided by the BOS that they were directed to by clinicians. The interviews demonstrated that participants saw the OIR as presenting a positive image of orthognathic treatment through the patient stories. The OIR was not seen as biased in terms of talking about perceived benefits and risks, as it was seen to accurately reflect participants' understanding of the longer-term benefits of surgery, while illustrating likely side-effects. As orthognathic surgery was seen to be low-risk, a positive image was seen to be appropriate. These findings may reflect that the majority of participants interviewed had decided to go ahead with treatment, including surgery, and therefore were already convinced about the potential benefits. Further research with patients who have rejected the option of orthognathic treatment for facial skeletal discrepancy may be useful.

The Patient Stories were seen to represent a range of experiences, and illustrate the positive outcomes of orthognathic treatment. Those who were considering treatment felt reassured by the OIR, while for those who were undergoing treatment, the OIR either did not affect or confirmed their decision. Patients expected to be happy with the results of their treatment and to feel more confident. It is possible that patients' expectations are being raised as a result of viewing the OIR, as participants reported not seeing negative experiences. Previous research has identified that realistic expectations are linked to patient satisfaction (Chen et al. 2002; Espeland et al. 2007). Therefore it is important that clinicians are aware that patients may perceive the OIR as presenting a positive image of orthognathic treatment.

The interviews showed that participants watched videos they found personally relevant, so it is important they know beforehand what type of surgery they are having. In order to help participants feel informed and ask pertinent questions, a link to the OIR should be given to patients at the first consultation. Nevertheless, we found no difference in opinions during the interviews in relation to malocclusion. Participants did not necessarily watch all the videos or look closely at the advice leaflets, and patients may miss useful information. A separate section on aftercare resources may be useful.

Use of the OIR should continue, but clinicians directing patients to the OIR should be aware of the content and the overall message that patients may take away. It may be useful to use a revised checklist to direct patients to specific resources, which could include Patient Journey videos or Patient Stories, as well as animations. It may also be helpful for clinicians to discuss responses to the OIR and any questions raised in a following consultation. There is no evidence as yet as to how this resource is being used by clinicians, and this could be an area for further research in order to provide a balanced view from professionals providing orthognathic treatment.

On the basis of this research, a questionnaire has been designed for ongoing evaluation of the OIR. The questionnaire has been designed to allow future viewers to feedback and improve the resource. Visitors to the website are asked about whether the OIR included the resources they were looking for and their opinions on the helpfulness of the different sections of the OIR.

Recommendations for BOS

Following the research, recommendations were made to the BOS to improve the OIR:

- Create a new aftercare resources section and separately list the checklists for clinicians on the main menu in order to make these resources easier to find.
- Add additional information about patients featured in the OIR to aid the understanding of prospective patients. Specifically:
 - Descriptions of the Patient Journey videos and information about patients (similar to Patient Stories).
 - Age range of patients during treatment to information in Patient Stories.

The overwhelming response to the OIR was positive, and several participants could not think of any improvements they would make. These are suggestions for additional content that some participants thought would be useful:

- More Patient Stories (specifically teenagers and young men).
- Additional photos within Patient Stories to show changes after orthodontic treatment and before surgery.
- Additional videos within the Patient Journey (a vlog showing a patient prior to surgery and being filmed talking about how they feel during the recovery process).
- Better signposting to information about nutrition and eating a balanced diet post-surgery in Aftercare Resources.
- A checklist for what patients need to have at home post-surgery in Aftercare Resources.

Limitations of the research

Identifying patients: Multiple participant identification centres risked a lack of congruence in the way patients were approached. This was addressed through the provision of detailed guidance for the clinicians involved in the project. Participant identification was dependent on which patients attended joint clinics. No male patients who were over 20 and pre-treatment, or under 20 and post-treatment were identified. However, nothing in previous literature suggests that patients in these groups would have been notably different.

Interviewing: Telephone interviews can elicit briefer answers than face-to-face interviews, and do not allow non-verbal cues to be recorded. However, the interviewer used follow-up questions to encourage participants to expand on their answers, and the average length of interviews was similar (27 minutes for face-to-face, 28 minutes for telephone). In the face-to-face interviews no non-verbal behaviour was recorded that had implications for the analysis, and there is no reason to suggest this would have been different in the telephone interviews.

Analysis: Only the research assistant read the transcripts in the initial stage of analysis. Nevertheless, the research assistant provided examples from the transcripts to the rest of the research team during analytic discussions to ensure that emerging themes reflected data generated from the interviews.

Translation to the whole population: Due to the qualitative nature of this research, the results of this study may not be transferable to the population as a whole. However, a purposive sample was collected, which aimed at heterogeneity in order to gain a wide range of views across the country.

Amount of content viewed: The research cannot offer a systematic comparison of all resources provided as part of the OIR as participants did not view all resources. However, across the sample, participants viewed a wide range of resources, and did not identify concerns about any particular resource.

Conclusions

The OIR was seen to be clear, easy to use and provide valuable content, in the form of reliable information and patient experiences.

The OIR was seen as a useful resource for patients considering orthognathic treatment, and potentially useful for patients undergoing treatment, although patients at this stage may already feel sufficiently informed.

The OIR was a trusted online resource and reassured patients by presenting what was perceived as a positive view of orthognathic surgery in which the benefits outweigh the risks.

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ORCID

Jennifer Kettle  <http://orcid.org/0000-0002-2776-1243>

Zoe Marshman  <http://orcid.org/0000-0003-0943-9637>

Philip E. Benson  <http://orcid.org/0000-0003-0865-962X>

Jonathan Sandler  <http://orcid.org/0000-0001-6278-1170>

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